



NOW THAT YOU KNOW: A Guide to Living with HIV

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NOW THAT YOU KNOW: A Guide to Living with HIV

We know that learning you are HIV positive can stir up many different feelings. Most of us felt angry, confused, and scared, but new medications and approaches to treating HIV have given us a new sense of hope. Now that you know, you may be thinking about what to do first and who to tell. You will be learning lots of important information including new medical terms, possible treatment options, and making new decisions. As a result, you may start to feel overwhelmed. But remember, you don't have to figure it all out today, and you don't have to do it alone.

This guide will help you through the first steps to living healthy with HIV, including:

- The importance of a strong support network
- Available support services
- What to look for in a doctor
- What to expect when getting into medical care
- Living safe and healthy with HIV

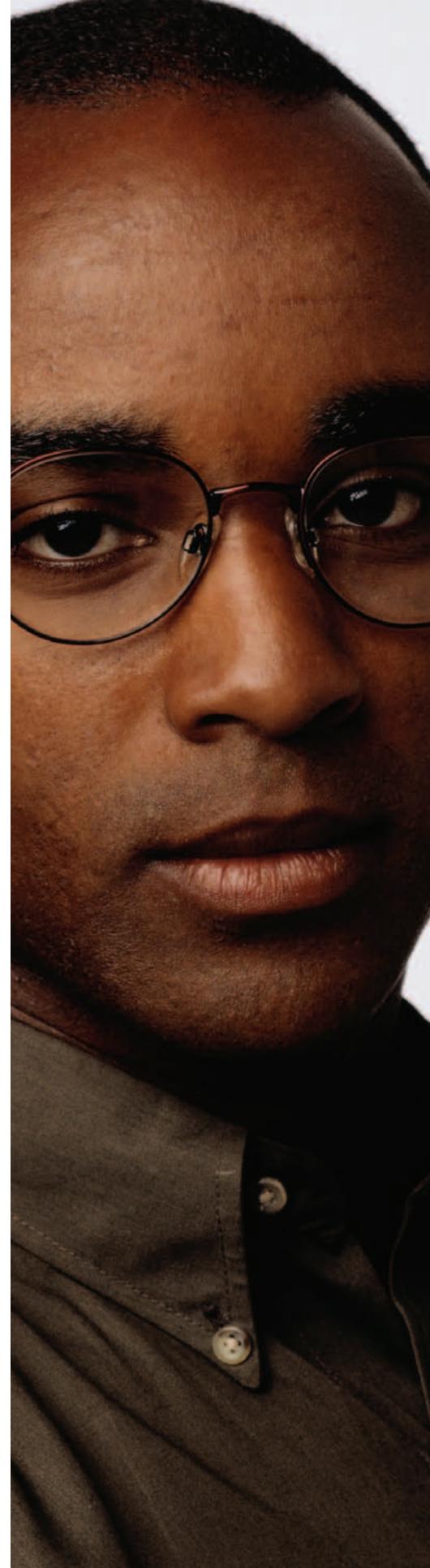
Some of the information in this guide may be useful today and some you may refer to as you begin making decisions about your health.

Accessing Support Services

There is no one way to address the emotional and physical impact of living with HIV. Some people get encouragement and support from family and friends. Others find it helpful to talk to another person living with HIV. Support groups for people living with HIV can provide a safe place to meet and connect with others living with HIV.

There are several HIV peer programs in Massachusetts that can connect you with someone in your area to talk to. There are also drop-in centers that offer a range of services including group meals, support groups, counseling, and social activities. There are prevention programs for people with HIV that can help you deal with being HIV positive and show you how to live a safe and healthy life.

To find out what is available in your area call the AIDS Action Committee Hotline at 1-800-235-2331, (TTY 617-437-1672) or go to www.aac.org.



Friends and family can also be a good source of support, but it can be hard to know how to tell people. There are some tips for how and when to disclose your status on page 14 of this guide.

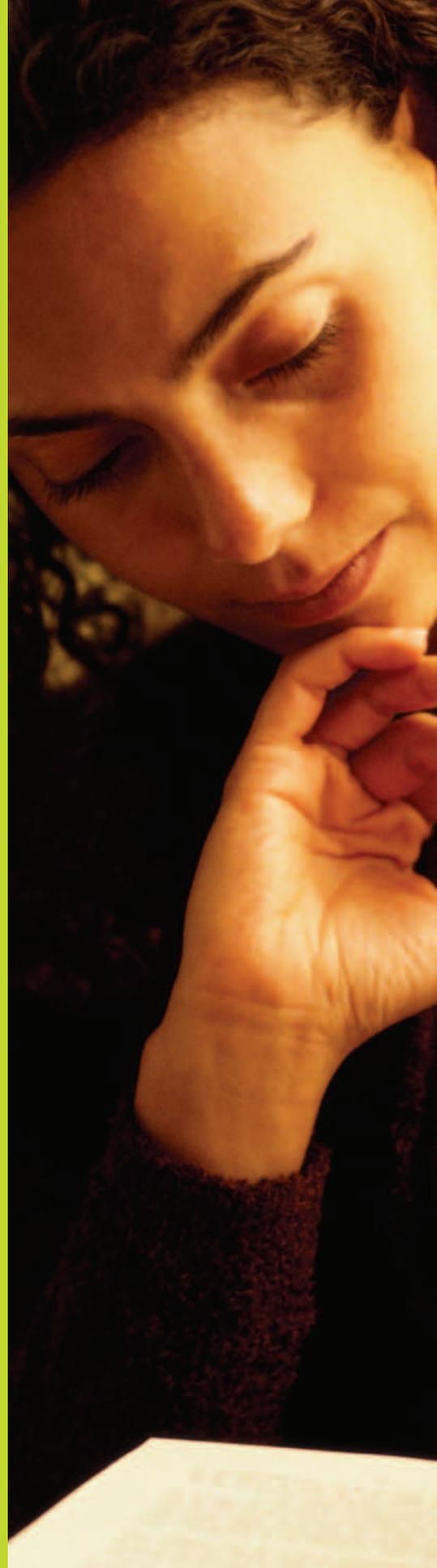
Whether you decide to tell your family and friends, or work with an agency, it's important to have a strong support network of people you trust.

There are people and places you can go to get the support and services you might need. HIV case managers are trained to identify what resources are available and work with you to determine which services you may need.

Your case manager can answer questions, help you find a doctor, and locate important services such as:

- Free or low-cost medical care
- Assistance with paying for medications
- Health insurance assistance
- Medication adherence programs
- Transportation and child care for doctor's visits
- Support groups
- Mental health and other counseling services
- Prevention programs for people living with HIV
- Food assistance
- Substance abuse treatment programs
- Needle exchange programs
- STD screening and treatment
- Hepatitis screening and vaccination

To find a case manager and identify resources available in your area, call the AIDS Action Committee Hotline at 1-800-235-2331, (TTY 617-437-1672) or go to www.aac.org.



Finding an HIV Doctor

Medical care for HIV can be complicated. That's why one of the most important things you can do is choose a doctor with experience in the treatment of HIV. Research shows that health care providers with more HIV experience provide better HIV care. So, if your current doctor is not an experienced provider of HIV care, he or she should consult regularly with an HIV expert or refer you to an HIV specialist.

Make sure you and your doctor have similar approaches to health care. You want a doctor who will listen, explain your options, answer your questions, and make decisions WITH YOU, NOT FOR YOU.

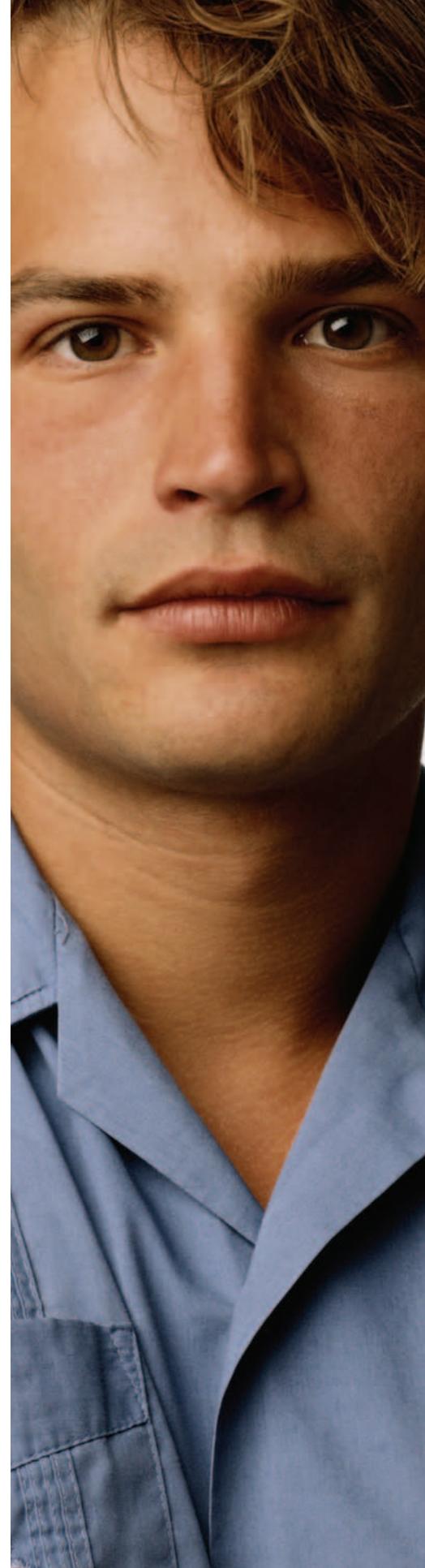
You want a doctor you can trust and talk to about your life, including any sexual and drug use activities. If you aren't able to be open about your life, you might not be getting the best and most personalized care. *The more your doctor knows about you the better care he or she can provide you.*

Your First Doctor's Visit

During your first visit, your doctor will want to do a general assessment of your overall health. Behaviors that put you at risk for HIV also put you at risk for other sexually transmitted diseases (STDs) and hepatitis. In order to determine if you need other services or screening for STDs, hepatitis or substance abuse, ***your doctor should know about your sexual and drug use history. This is important information because if you are fighting multiple infections or conditions, your body will not be able to fight the HIV as well and you may get sicker, faster.*** So get checked regularly since hepatitis symptoms may not show up for many years, and not all STDs have symptoms.

Information you share with your doctor is confidential and is protected by state and federal privacy laws. If you have questions about the confidentiality of your information, ask your doctor.

To find out more call the Division of STD Prevention at 1-866-749-7122 or go to www.mass.gov/dph/cdc/std/divstd.htm.



Monitoring HIV

To get a first look at how you are doing, your doctor will want to do several tests. The two most common tests used to monitor HIV and determine whether or not you should begin taking HIV drugs are the T-cell and viral load tests.

The T-cell test counts infection-fighting white blood cells called T-cells or CD4 cells. A falling T-cell count can be a sign that HIV is damaging your immune system. The viral load test measures the amount of HIV in your blood and how quickly it is multiplying.

To get the most accurate results, your doctor will do these tests two or three weeks apart. This is called baseline testing. After your baseline is established, your doctor will probably do these tests every three months to continue monitoring your health.

When you get your blood work results, your doctor will explain them to you, and together, you will consider your treatment options.

Choosing a Treatment Plan

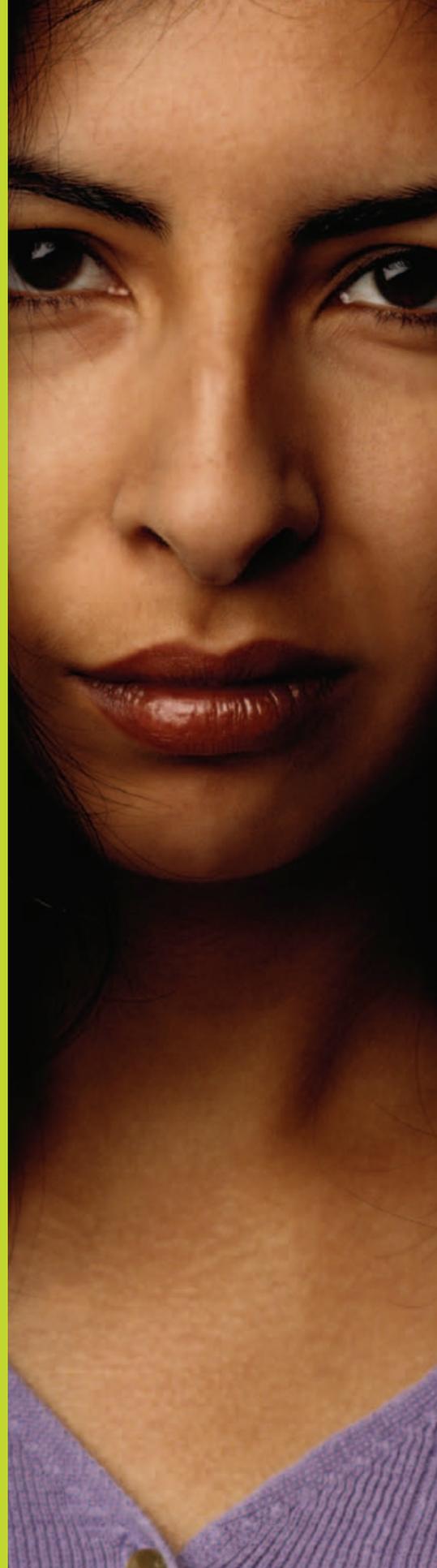
Deciding whether or not to start treatment is based on several factors, including blood work results and your readiness to start taking medications. Before deciding on your treatment plan make sure you understand how the drugs work and why you need to take them. Talk to other people with HIV about what drugs they are taking and how they manage taking them, read about the treatment being recommended to you by your doctor, and go to HIV websites. Be sure your doctor knows how you feel about using medications and about other treatments you are using or want to try, including non-medical treatments like vitamins and herbs.

Many HIV medications can cause side effects. Knowing what side effects you are willing to tolerate may be an important factor in considering if you are going to start taking medications or

which medications you and your doctor choose. The most common side effects include nausea, diarrhea, and headaches. There are other side effects that may impact your long-term health. Ask your doctor to explain all the possible side effects of the drugs you are taking and ways that can help you manage them.

Some individuals have a form of HIV that is resistant to certain HIV drugs. This means that the drugs will not work against the virus. Others may become resistant to certain drugs because the drugs were not taken correctly or are no longer working. In order to determine what treatment plan is right for you, your doctor may want to do a drug resistance test to see if your virus is resistant to any HIV drugs.

Fortunately, there are more treatment options available for people living with HIV than ever before. ***While HIV drugs are far from perfect, we know people can live longer and healthier by choosing the right treatment plan and sticking with it.***

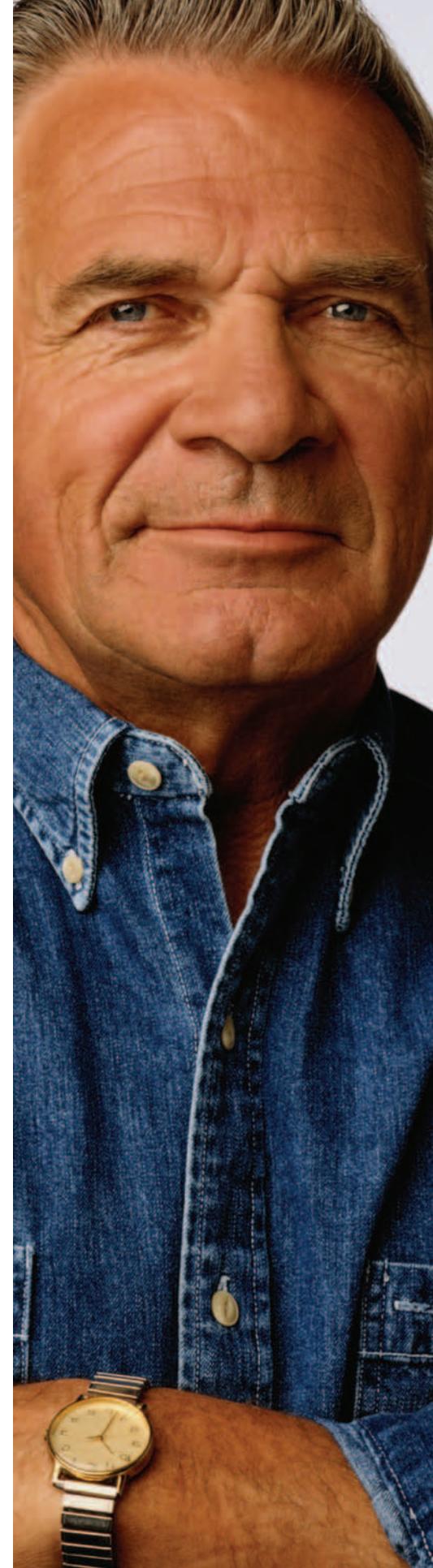


Here are some considerations when deciding on a treatment plan:

- Most of the HIV drugs can be taken twice a day and others three times – are you able to take drugs three times a day?
- Some drugs need to be refrigerated. Do you live and/or work in a place that has a refrigerator?
- Some drugs need to be taken with food and others on an empty stomach. Is your eating schedule flexible?
- Can you put up with the drug's side effects?

Here are some questions to ask once you and your doctor have chosen a treatment plan:

- How much should I take?
- What times should I take it?
- Should this be taken with or without food?
- Can this drug react with other drugs or anything else I may be taking?
- What are the possible side effects?
- What are the possible long-term side effects?

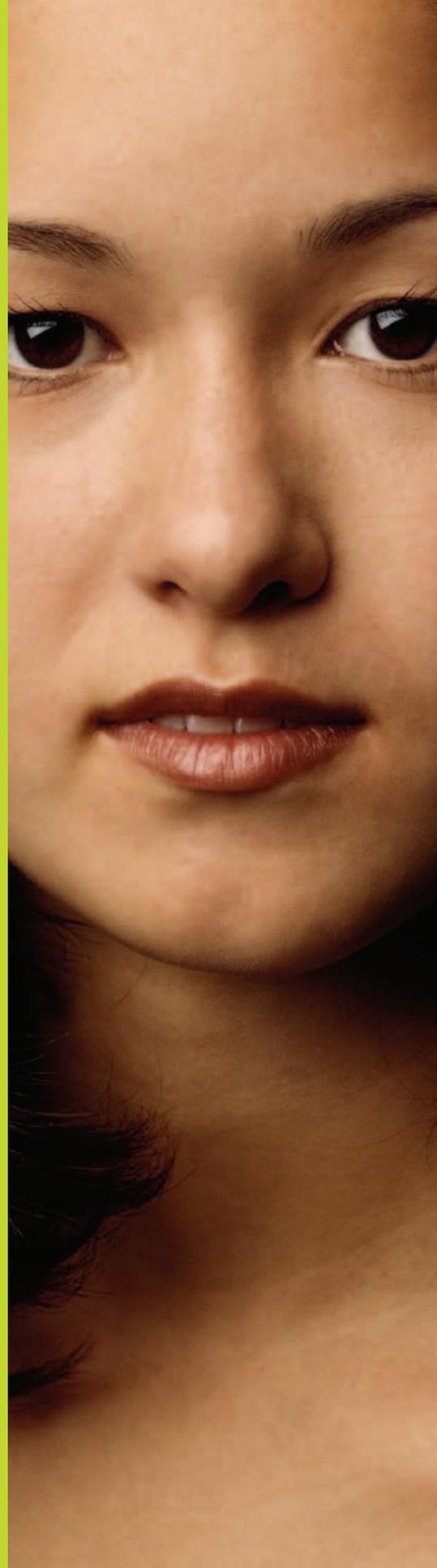


Understanding Treatment Adherence

Once you have started taking your HIV drugs, it is important that you take each drug as prescribed by your doctor: every dose, every day and according to instructions. This is called treatment adherence. If you don't take your medication as prescribed, you may become resistant to the medication. This could limit your future treatment options.

Side effects may be the biggest reason why some people stop taking their drugs. If you are having side effects or a hard time sticking to your treatment plan, be sure to talk to your doctor. You and your doctor can talk about other HIV treatment options that might work better for you.

It's important not to change or stop your medications without talking to your doctor.



Here are some tips on how to stick to your treatment plan:

- Make a list of what drugs you take, when you need to take them, and check it everyday.
- Ask about things that can help, like pillboxes, timers, or support groups.
- Ask people you trust to help you remember to take your medication.
- Ask your doctor what you should do if you forget or miss a dose of your medication.

Understanding Hepatitis & HIV

The three most common types of hepatitis, or inflammation of the liver, caused by viruses, are hepatitis A, B and C. There are vaccines for hepatitis A and B, but not C. Check with your doctor about being screened and vaccinated. Some people have both hepatitis C (Hep C) and HIV. Like HIV, people get Hep C through contact with blood. Hep C is easily spread when people who use drugs share works, including needles, cotton, and cookers. Although Hep C can also be passed through sex, this is uncommon. There is no vaccine for Hep C, but there are things you can do to keep your liver healthy and available treatments that can be effective. For people with HIV, Hep C may cause liver damage more quickly. This damage to the liver could make it more difficult to take anti-HIV medication. Treating both HIV and Hep C is complicated, so if you think you might have hepatitis, be sure to tell your doctor.

To find out more about hepatitis, call the Hepatitis Hotline at 1-888-443-HEPC (4372) or go to www.masshepc.org.

Telling Others

As you begin building your support network, you will need to consider who you are going to tell. This decision can be hard. ***You don't have to tell everybody. Take your time to decide who to tell and how you will approach them. Be sure you're ready.***

Here are some things to consider when deciding who to tell:

- **Know why** you want to tell them.
What do you want or need from them?
- **Anticipate** their reaction. What's the best reaction you could hope for? The worst you might have to deal with?
- **Prepare** yourself. Get informed about your health. You may want to have information ready to give the people you tell like a pamphlet or hotline number.
- **Get support.** Talk it over with someone you trust or others who are HIV positive and come up with a plan.
- **Encourage** any sexual or drug-sharing partners to get tested. You can tell them yourself or have someone from the health department tell them without saying anything about you.
- **Accept** the reaction. You can't control how others will deal with your news.



Staying Healthy and Keeping Your Partner Safe

HIV does not spread easily from person to person. HIV is found in blood, semen (cum), vaginal fluid or breast milk. In order to pass or get HIV, it has to get into your body or your partner's body. HIV can also be passed from mother to child during pregnancy, delivery and through breast-feeding. But there are ways to make sure you and your sex and/or drug using partners stay safe.

Lowering your risk of passing HIV to others may mean changing the way you have sex or use drugs. This can be hard, but you should be sure your partners do not come in contact with your blood or sexual fluids.

To lower your risk of passing HIV to others:

- Talk with your partners about being HIV positive.
- Ask your partners about their health.
- Decide with your partners what you are willing to do to stay safer.
- Use condoms during anal or vaginal sex.
- Do not share needles or works, including cotton, cooker or water.

For women who are pregnant or considering pregnancy:

Getting treatment at any point in your pregnancy will give you a better chance of having a healthy baby, so:

- Ask your doctor about new treatments.
- Talk with your doctor about ways to keep you and your baby healthy during pregnancy and after giving birth.
- Continue your prenatal care throughout your pregnancy.



NOW THAT YOU KNOW

Now that you know, you can be in control. What you want out of life doesn't have to change because you have HIV. Take steps toward living a safe, full and healthy life. The next step is yours. We hope this guide has given you the information and resources you need to find a doctor, to tell a friend or family member, to think about treatment options, to keep you and your partners safe, and to find the support you need. Living with HIV can be complicated, but you are in control.

RESOURCES & SUPPORT SERVICES

MA STATEWIDE HOTLINES

AIDS Action Committee

1-800-235-2331 (English, Spanish)
TTY: 617-437-1672
www.aac.org

Massachusetts Hepatitis C Hotline

1-888-443-HEPC (4372)
TTY: 617-437-1672
www.masshepc.org

Massachusetts Substance Abuse Information & Education Helpline

1-800-327-5050 TTY: 617-536-5872
www.helpline-online.com

PRIMARY HEALTH CARE

ACT Now Centers

The ACT Now Program (Access to Care and Treatment NOW) provides free and confidential primary care to people who are HIV+ and uninsured.

GREATER BOSTON

Boston Medical Center

Boston: 617-414-4290
Spanish, Portuguese, French, German, Haitian Creole

Cambridge Health Alliance

Cambridge: 617-665-1606
Spanish, French, Haitian Creole, Portuguese

Fenway Community Health Center

Boston: 617-927-6000
Spanish

CENTRAL REGION

Metrowest Health Center

Framingham: 508-383-1145
Spanish

UMMHC University Hospital

Worcester: 508-856-6027
Fitchburg: 978-665-5957
Spanish, French (Fitchburg only)

NORTHEAST REGION

Greater Lawrence Family Health Center

Lawrence: 978-686-0090
French, Spanish, Cambodian, Taiwanese, Italian, S-Swa, Lebanese, Gujar, German, Chezlk, Farsi, Punjabi, Russian, Lingala, Indo, Urkra, Korean, Hebrew

Lynn Community Health Center

Lynn: 781-581-3900
Spanish, Khmer, Farsi, Shona, Ndebele, Bulgarian, Portuguese

Lowell Community Health Center

Lowell: 978-970-2730
English, Spanish, Portuguese, French, Luganda, Swahili, Shona, Hindi

SOUTHEAST REGION

Cape Cod Hospital, Infectious Disease Clinical Services

Hyannis: 508-862-5650
Portuguese, Spanish

Greater New Bedford Community Health Center

New Bedford: 508-992-6553 x133 or x186
Spanish

Morton Hospital

Taunton: 508-828-6733

Outer Cape Health Services

Provincetown: 508-487-9395
Spanish, French

Stanley Street Treatment and Resources (SSTAR)

Fall River: 508-675-1054
Spanish, Portuguese

WESTERN REGION

Baystate Medical Center

Springfield: 413-794-5531
Spanish

Holyoke Health Center

Holyoke: 413-420-2154
Spanish

HIV SUPPORT SERVICES

HIV Support Services can include services such as:

- Case Management
- Transportation Assistance
- Food Assistance
- Alternative Therapies
- Child Care
- Client Advocacy
- Housing Advocacy
- Emergency Assistance
- Adult Day Care
- Mental Health Services
- Drop-in Centers
- Peer Support

GREATER BOSTON

AIDS Action Committee (AAC)

Boston: 617-437-6445
Spanish, Haitian Creole, French, Portuguese

Boston Living Center (BLC)

Boston: 617-236-1012
Spanish

Cambridge Cares About AIDS (CCAA)

Cambridge: 617-661-3040
Spanish, Portuguese, French, Haitian Creole, Luganda, Chichewa, Swahili, Shona, Amharic

Cambridge Health Alliance

Cambridge: 617-591-6768
Portuguese, Haitian Creole, Spanish

Center for Community Health, Education & Research (CCHER)

Dorchester: 617-265-0628
French, Haitian Creole

Children AIDS Program (CAP)

Mattapan: 617-534-2050 x23
French, Haitian Creole, and Spanish

Community Servings, Inc.

Roxbury: 617-445-7777
Spanish

Dimock Community Health Center

Roxbury: 617-442-8800
Spanish, Haitian Creole

Fenway Community Health Center

Boston: 617-267-0900
Spanish, French, and Haitian Creole

Harbor Health Services, Inc.

Dorchester: 617-282-3200
Haitian Creole, Vietnamese, Portuguese, Spanish

Home for Little Wanderers (HFLW)

South End: 888-HOME-321 or
617-267-3700
Spanish, Portuguese, Haitian Creole

Justice Resource Institute (JRI)

Boston: 617-457-8150
Spanish

Pathways to Wellness/AIDS Care Project

Back Bay: 617-859-3036
Cantonese, Spanish, Portuguese, French, Russian

SPAN, Inc.

Boston: 617-423-0750
Spanish

CENTRAL REGION

AIDS Project Worcester

Central and South Worcester:
508-755-3773
Spanish

CARE AIDS Services-Fitchburg

North Worcester County:
978-345-4366
Spanish
617-376-2000, ext.2040

Metrowest Latin American Center

Metrowest & Blackstone Valley:
508-875-3700
Spanish, Portuguese

NORTHEAST REGION

Greater Lawrence Family Health Center

Lawrence: 978-688-6768
Spanish, Portuguese, Cambodian, Vietnamese, Taiwanese, French, German, Hebrew, Italian

Lowell House

Lowell: 978-459-8656
French, Spanish

Lynn Community Health Center

Lynn: 781-596-2502 x729
Spanish, Russian, Khmer

VNA Care Network/OASIS

Danvers: 1-888-663-3688 x1347
Spanish

SOUTHEAST REGION

AIDS Support Group of Cape Cod (ASGCC)

Provincetown: 508-487-9445
Hyannis: 508-778-1954

Brockton Area Multi-Services Inc. (BAMSI)

Brockton: 508-580-0219
Spanish

Community Counseling of Bristol County

Taunton: 508-884-8264
Portuguese, Spanish

Nantucket AIDS Network

Nantucket: 508-228-3955
Portuguese

New Bedford AIDS Consortium

New Bedford: 508-979-5083
Spanish, Portuguese, Creole

Quincy South Shore AIDS Consortium

Quincy: 617-376-2000 x2040

South Shore AIDS Project

Plymouth: 508-747-2211
Spanish

Stanley Street Treatment & Resources (SSTAR)

Fall River: 508-679-5222
Portuguese, Spanish

WESTERN REGION

AIDS Care/Hampshire County

Northampton: 413-586-8288

Athol Memorial Hospital

Athol: 978-249-3511
Polish, Spanish, Portuguese

Red Cross – Berkshire County

Pittsfield: 413-442-1506

River Valley Counseling Center

Holyoke/Chicopee/Westfield:
413-540-1214
Springfield: 413-737-2437
Spanish

Tapestry Health Systems

Greenfield: 413-773-8888
Spanish

HOUSING FOR PEOPLE WITH HIV/AIDS

STATEWIDE

AIDS Housing Corporation
617-927-0088 www.ahc.org

HIV COMPREHENSIVE HOMEHEALTH PROGRAMS

The HIV Comprehensive Homehealth Program provides physician referred home-based nursing services and homemaker/Life Skills Advocacy services for persons living with HIV.

BOSTON REGION

All Care VNA and All Care Resources
Lynn: 781-598-2454
Spanish, Portuguese, Italian, French, Creole, Filipino, Ukrainian, Greek, Polish, Russian

Uphams Corner Health Center
Dorchester: 617-825-9206
Spanish, Portuguese, Creole, French, Vietnamese

VNA Care Network
Cambridge: 1-888-663-3688 x 6842

CENTRAL REGION

Diversified Visiting Nurse Association - Healthy Directions
Fitchburg: 978-348-1702

VNA Care Network
Worcester: 1-888-663-3688

NORTHEAST REGION

Homehealth VNA
Lawrence: 978-552-4000
Spanish

VNA Care Network
Danvers: 1-888-663-3688

SOUTHEAST REGION

Nantucket AIDS Network
Nantucket: 508-228-3955

Town of Provincetown
Provincetown: 508-487-7086
Hyannis: 508-957-7509

WESTERN REGION

River Valley Counseling Center
Holyoke: 413-737-2437
Spanish

Cooley Dickinson Hospital – AIDS CARE/Hampshire County
Northampton: 413-586-8288

OTHER HEALTH INSURANCE AND ASSISTANCE

Massachusetts HIV Drug Assistance Program (HDAP)
1-800-228-2714
www.crine.org/info/drug.html

Comprehensive Health Insurance Initiative (CHII)
1-800-228-2714
www.crine.org/info/drug.html

MassHealth
1-800-841-2900
TTY: 1-800-497-4648

HIV Dental Ombudsperson Program
617-534-4717

HIV POST-EXPOSURE PROPHYLAXIS (PEP)

All ACTNow centers listed above can provide post-exposure prophylaxis, in addition to most hospital emergency rooms. For clinical consultation regarding administering PEP, clinicians should call the National Clinician's PEpline: 1-888-448-4911.

Perinatal HIV Provider Information Line
Brigham and Women's Hospital
1-800-742-2211

Research and Information AIDS Action Committee HIV Health Library
1-866-799-0079
617-450-1432
www.aac.org
reslib@aac.org
Information and consultation on HIV treatment, nutrition, adherence and other HIV and health-related information

Boston AIDS Consortium
617-867-0144 or 1-800-869-2849
www.bacboston.org

CLINICAL TRIALS

AIDS Clinical Trial Information Service
1-800-874-2572
TDD: 1-800-243-7012

Community Research Initiative of New England (CRI)
1-888-469-6577
TTY: 617-778-5460
www.crine.org

NEEDLE EXCHANGE PROGRAMS

In addition to the exchange of new syringes for used ones, needle exchange programs offer HIV counseling and testing, referrals to substance abuse treatment, hepatitis C education, harm reduction strategies, and bleach kits.

Boston Public Health Commission
Boston: 617-771-2138 or 1-800-383-2437

Cambridge Cares About AIDS

Cambridge: 617-661-3040 or 617-680-1063

Tapestry Health SystemsNorthampton: 1-800-696-7752 or
413-586-0310 x106**AIDS Support Group of Cape Cod (ASGCC)**Provincetown: 508-487-8311 or
1-866-NO-TO-HIV (1-866-668-6448)
Mid and Upper Cape: 508-274-5428
(IDU Registration only)**PARTNER CONSELING AND
REFERRAL SERVICES (PCRS)****HIV/STD Partner Notification**Greater Boston 617-983-6940
Northeast 508-851-7261 x36, x37
Southeast 508-977-3704
Central 508-854-3300 x105
Western 413-784-3846
Pittsfield 413-447-2654**LEGAL ASSISTANCE
RELATED TO HIV/AIDS****Gay & Lesbian Advocates & Defenders**617-426-1350
www.glad.org**JRI Health Law Institute**617-988-8700
www.jri.org**The HIV/AIDS Law Consortium
of Western Massachusetts**

1-800-633-1890 or 413-732-0011

Legal Action Center212-243-1313
lacinfo@lac.org
www.lac.org**MASSACHUSETTS
STATE AND CITY AGENCIES****MDPH HIV/AIDS Bureau**617-624-5300 TTY: 617-624-5387
www.mass.gov/dph/aids**MDPH HIV/AIDS Surveillance Program**Main Line: 617-983-6560
Data Request: 617-983-6583
www.mass.gov/dph/aids/aidsprog.htm**MDPH Hepatitis C Program**1-888-443-HEPC (4372)
www.masshepc.org**MDPH Immunization Program**617-983-6800
http://www.mass.gov/dph/cdc/epiimmz.
htm**MDPH Division of STD Prevention**1-866-749-7122 or 617-983-6940
http://www.mass.gov/dph/cdc/std/divstd.
htm**MDPH Bureau of Substance Abuse
Services**617-624-5111
TTY: 617-536-5872
www.mass.gov/dph/bsas**MDPH MassCare
(Massachusetts Community AIDS
Resource Enhancement) Program**617-994-9819
TTY: 617-624-5992
www.mass.gov/dph/bfch/shn/masscare**Boston Public Health Commission**617-534-5395
TTY: 617-534-9799
www.bphc.org**NATIONAL HOTLINES****AIDS Hotline for Teens**

1-800-234-TEEN (8336) M-S 4-8pm CST

AIDS Treatment Information Service1-800-448-0440
TTD: 1-800-243-7012**CDC National HIV/AIDS Hotline**English 1-800-342-AIDS (2437)
Spanish 1-800-344-SIDA (7432)
TTY: 1-800-243-7889**CDC National STD/HIV Hotline**

1-800-227-8922

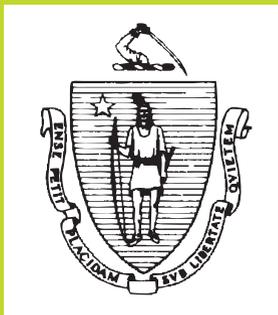
CDC National Hepatitis Hotline

1-888-4HEPCDC (888-443-7232)

RESEARCH AND INFORMATION**AIDS Action Committee HIV Health
Library**1-866-799-0079
617-450-1432
www.aac.org
reslib@aac.org**Boston AIDS Consortium**617-867-0144 or 1-800-869-2849
www.bacboston.org**National Institute on Drug Abuse (NIDA)**301-443-1124
www.nida.nih.gov**Substance Abuse & Mental Health
Services Administration (SAMHSA)**301-443-8956
www.samhsa.gov**FREE BROCHURES AND
POSTERS****Massachusetts
Health Promotion Clearinghouse**1-800-952-6637
TTY: 617-536-5872
Fax: 617-536-8012
Customer Service: 617-536-0501 x211
www.maclearinghouse.com

Get Tested. Get Care. Get Support.

**For additional information
& resources, call 1-800-235-2331.**



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Massachusetts Department of Public Health**

2004 - ENGLISH

